PARTICIPANT EXPERIENCE SURVEY
BRAIN INJURY VERSION
USERS' GUIDE

May 10, 2005

ACKNOWLEDGEMENTS

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1. Purpose of the survey

The purpose of the Participant Experience Survey for persons with brain injuries (*PES-BI)* is to provide State officials information about waiver participants' experience with the services they receive under the 1915(c) waiver program -- the Medicaid Home and Community-Based waivers.

❖ Measures waiver participants' experience in four domains:

- **Program Supports**: Assesses waiver participants' experience with housing, case manager access, and access to additional services and equipment.

- **Choice and Control:** Assesses whether waiver participants have control over decisions about how they live their lives and their ability to make choices about the services they receive and who provides them.

- **Respect/Dignity**: Assesses whether providers treat waiver participants with respect and whether waiver participants experience abuse.

- **Community Activities**: Assesses experience with employment, transportation, and opportunities for community involvement.

❖ Additional, specific questions in two domains:

- **Community Integration/Inclusion**: Do waiver participants have the opportunity to participate in activities and events outside their homes that they choose and enjoy?

- **Access to Care**: Are waiver participants' needs for personal assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) being met?

❖ One tool that States may consider using as part of their quality improvement program to monitor quality in their waiver programs.

❖ Target population is adults with acquired brain injuries.[1]

❖ Developed by The MEDSTAT Group, Inc. (Medstat) for The Centers for Medicare and Medicaid Services (CMS), a division of the Department of Health and Human Services.

❖ The PES BI can be used to calculate up to 58 performance indicators within the domains, for quality monitoring and intervention. These indicators can be calculated for the entire sample, or for different sub samples, such as program participants

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[1] Acquired brain injuries include both traumatic brain injuries, as well as those caused by strokes, tumors, and other non-traumatic causes.

residing in different counties or served by different providers, and compared across groups. Section 7 lists the indicators and *Appendix V* includes information on calculating and interpreting them.

PES BI and the Quality Improvement Process

The Quality Framework, released by CMS in 2003, articulates several dimensions of quality within HCBS waivers, and lays out a process for building quality into the waiver program[2]. This process comprises four basic steps:

> ❖ Design.
> ❖ Discovery
> ❖ Remediation
> ❖ Improvement

That is, quality oversight is built into the program <u>design</u>, various tools and techniques are used to <u>discover</u> problems with quality, problems are <u>remediated</u> at the individual level, and analysis of individual and systemic data lead to quality <u>improvements</u> system-wide. The PES BI and the resulting performance indicators can be useful for the second and fourth steps in this process, *discovering quality problems* and *systemic quality improvements*. Quality improvement interventions are most credible when they are grounded in evidence. Such evidence is generated from the discovery process, when data from individuals is aggregated system-wide. The PES BI data can be used to identify areas where program participants are experiencing unmet need or other problems. Any problems can then be addressed systemically across the waiver as a whole, as well as on an individual basis. Evidence, including the PES BI performance indicators, helps allocate scarce quality improvement dollars appropriately.   For more detailed guidance on developing quality improvement projects, see **Work Book: Improving the Quality of Home and Community Based Services and Supports,**[3] developed by the Muskie School under contract to CMS.

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[2] The Quality Framework can be found on-line at http://www.cms.hhs.gov/medicaid/waivers/frameworkmatrix.asp
[3] Maureen Booth and Julie Fralich "Work Book: Improving the Quality of Home and Community Services and Supports." Prepared for the Centers for Medicare and Medicaid Services. 2003. Available at http://www.cms.hhs.gov/medicaid/waivers/hcbsworkbook.asp

2.   **<u>Selecting Your Sample</u>**

Gathering data on the experiences of the waiver population does not always require actually interviewing all waiver participants. In most cases, except when the waiver population is very small, it will be sufficient to interview just a representative sample. The first step in this process is to define the sampling frame - the group of people from whom you will select your sample. To help with defining the sampling frame, it is important to clarify goals and constraints for the survey process. Some questions to consider:

- ❖ What do you want to be able to say based on the results?
    - o Do you want to profile your entire waiver population, or only a subset?
    - o Do you want to compare sub-groups within the waiver population?

- ❖ Who will be your audience for the results?
    - o Policymakers, providers, program participants, advocacy groups, CMS?
    - o What are their expectations for the survey?

- ❖ What are your constraints for the survey process?
    - o Financial and staffing constraints?
    - o Geographic constraints? – Reaching a geographically dispersed population can be expensive.
    - o Political and other constraints?

- ❖ Do existing data from other sources suggest a specific target population?
    - o Additional information may indicate the need to look only at a particular type of program participant.
    - o Example: residents of rural areas, managed care enrollees, program participants over a certain age.

Guidelines for determining sample size and composition, following this clarification process, are outlined below.

- ❖ Random samples are ideal.
    - o Allow you to draw inferences about your entire waiver population.
    - o May not be financially or logistically possible.

- ❖ Larger samples allow for greater precision in estimates.
    - o Precision is a function of confidence level (95% is most common) and confidence interval (margin of error, e.g. +/- 5%)
    - o Sample size calculators can determine necessary sample size, given population, and desired confidence level and interval. A user-friendly version is available on-line at http://www.surveysystem.com/sscalc.htm

- ❖ Analysis of sub-groups may require larger samples
  - o May need to stratify sample by dimension of interest.
  - o Stratifying ensures you have enough respondents of each type to make valid estimates of a subpopulation.
  - o Examples of dimensions for stratifying: provider, type of provider (e.g. non-profit, for-profit, independent), county of residence, age group.
  - o Stratifying can be a complicated process – local academic experts or survey professionals may be able to help.

Any criteria you select for including or excluding program participants from the sampling frame must be consistently applied and explicitly articulated. Your findings will <u>only</u> apply to those who meet your criteria. For example, if you exclude program participants who do not speak English, then you can only present your results as representative of the English-speaking waiver population.

Addressing Cognitive Impairments

For the sake of simplicity, states may be tempted to limit the survey sample to cognitively intact program participants. However, we recommend against this approach for several reasons. First, the PES BI was designed to be accessible to the largest number of program participants possible, including those with cognitive limitations. The language and response patterns have been extensively tested to insure that they are straightforward and concrete. Second, as an explicitly *participant survey*, with no proxy version, the goal of the instrument is to allow program participants to comment directly on their experiences whenever possible. Finally, it may not be possible or practical to determine in advance which participants are cognitively intact.

3.   **Choosing and Training Interviewers**

After defining your target population (the sampling frame) and selecting your sample, it is important to invest in selecting the appropriate people to conduct the interviews. Survey findings are only as good and credible as the combination of the instrument and how it was administered. Indeed, poor interviewing can distress clients and possibly decrease satisfaction. This may be especially true of individuals with acquired brain injuries, who are often predisposed to being frustrated with their lives post-injury. In addition, participating in the survey can potentially be both cognitively and emotionally draining. Therefore, carefully selecting and training interview staff will be essential to a successful survey process.

Choosing Interviewers

- ❖ The PES BI is designed to be administered in person.
  - o Interview staff with strong interpersonal skills are essential.
  - o Because of the potentially emotionally-charged content of portions of the survey, it is important that interviewing staff be able to maintain a positive affect throughout the survey process.

- ❖ You may face trade-offs between cost, skill, and experience.
  - o Personality and experience relating to people with brain injuries, especially around behavioral and memory issues, may be more important than extensive interviewing experience.

- ❖ Some important factors to consider when choosing interviewers:
  - o Interviewers must be experienced and comfortable with interacting with people with acquired brain injuries.
  - o They should be able to develop and maintain rapport with the waiver participant throughout the interview.
  - o Interviewers should be appreciative of the program participants' perspective and be able to address any anxieties around the interview process.
  - o Good interviewers will understand their role is to gather information and not to address service problems during the interview.
  - o Neutrality is paramount: interviewers should not have their own agendas with respect to the information gathered.
  - o Interviewers must also be sensitive to the cultural issues and settings of the program participants with whom they will be meeting.
  - o Licensed professionals, such as nurses and social workers, may have legal obligations around reporting some of the things they see and hear, such as alleged abuse and neglect. These obligations should be reviewed during interviewer training.

An ideal interviewer will be warm, respectful, caring, and professional. S/he should be a good listener, who understands the purpose of the survey process (to collect data), and who can engage

the program participants and stay focused on the topic despite interruptions and distractions. S/he should respect the differing cultures of the program participants. Finally, s/he should be able to probe for additional information when necessary, to obtain the most complete accurate information, without biasing the waiver participant's responses.

Important:

Interviewers should never be anyone involved with direct provision of services to the program participant being interviewed. Case managers, supports coordinators, or direct care staff should not function as interviewers because of a potential conflict of interest, and the need to provide a safe environment for program participants to answer honestly.

What about peer interviewers?

Some states may consider using peer interviewers during the survey process. Peer interviewers have the advantage of empathy and understanding with the sample population. However, there are a few caveats about using this group. First, interviewers must have no agenda with regards to survey findings, which could bias how questions are asked and responses coded. Second, peer interviewers need training and support to avoid projecting their experiences onto survey respondents. Finally, as with all interviewers, it is important to stress professional interviewing norms, which are outlined in the training guide below.

Training Interviewers

- ❖ Training should be in-person.
    - o Trainers should include waiver program and quality assurance staff, who can explain the role and goals of the survey, as well as survey and interviewing experts.
    - o Include a model interview with a volunteer program participant if possible.

- ❖ Sections 4, 5, and 6 of this guide are designed as a template for interviewer training. *Appendix I* provides more details on the survey experience for respondents.

Monitoring Interviewers

As essential as training interviewers is, monitoring their work and providing appropriate guidance and feedback is just as critical. Some techniques for interviewer guidance and monitoring:

- ❖ Use mentors: Have new interviewers accompany more experienced interviewers to observe before going out on their own. Also, have more experienced interviewers observe the first few interviews done by new staff. Multiple interviewers should compare coding afterwards, and discuss any differences in their interpretation of responses.

- ❖ Tape interviews and review with a more experienced interviewer for feedback and suggestions.

- ❖ Solicit feedback directly from selected program participants about their interview experience.

NOTE: The following three sections are designed to be a training guide for interviewers administering the PES BI instrument. This guidance is directed specifically at the people who will be conducting the interviews. In general these guidelines are recommendations only; states and other users should feel free to adapt these materials as appropriate. These pages can be removed from this guide and used separately.

4.   **Scheduling and Preparing for the Interviews**

Collecting pre-survey data

❖   Complete first section of the face sheet (if appropriate).

Face sheets are useful for providing background information to the interviewer, prior to scheduling and conducting the interview. *Appendix II* of this guide includes a sample survey face sheet, which can be modified to reflect program specifics. If face sheets are being used, the first section should be completed by the case manager or other knowledgeable agency/waiver staff for each individual selected into the sample. The sample face sheet in *Appendix II* includes items helpful for arranging interviews, such as the program participant's address and phone number.

Scheduling interviews

Survey participation, and therefore response rates, will be enhanced if waiver participants are educated about the survey before the actual interview. Concern or confusion about the survey process can be addressed in advance, through letters or personal contact with participants selected into the sample.

❖   Call program participants or send a letter to introduce survey.

Call or send a letter to program participants selected into the sample, letting them know who will be contacting them about their interest in the survey and to schedule an interview. A sample letter is included in *Appendix III*. Contacting participants before they are scheduled for interviews provides an opportunity to explain the purpose of the survey and answer any questions they may have. This may in turn increase their likelihood of agreeing to participate. Initial contact about the survey may be more effective if it comes from someone the program participant knows and trusts, such as a case manager, family member, or favorite staff person.

❖   Contact the guardian if necessary.

If a guardian's consent is required, this consent should be obtained prior to meeting or speaking with the program participant. Contact the guardian first to

introduce the survey and its use. Case managers can also play an important role in obtaining guardian consent.

❖ <u>Call the program participant to set an interview time</u>

Use the face sheet information, if appropriate, to call the program participant, or the appropriate designee, and introduce yourself and the PES BI. A suggested script is included below. For some individuals with severe cognitive disabilities, it may be preferable to arrange interviews through agency staff or an informal caregiver.

> "Hello, my name is _____. I am calling on behalf of the State of _____ to see if you are willing to answer some questions about the services you receive from agencies like _____ (name agency.) Did someone let you know I might be calling?
>
> These questions ask if you are satisfied with the services you receive, if staff treat you well, and if you are getting the assistance you need. _____ wants to use this information to evaluate their program providing help to people with brain injuries who live in the community. This information will help determine if any changes need to be made to improve the program.
>
> These questions should take about 30 minutes of your time. It is your choice whether or not you answer these questions. The information you give me will be kept confidential. If you are willing to answer the survey, we can meet at a time and place that works for you.
>
> I am really interested in hearing your opinions and about your experience. When is a convenient time for us to talk?"

❖ <u>Arrange an interview time and location.</u>

If the program participant is willing to be surveyed, arrange a time to meet with him/her at a location that is both convenient and comfortable.

- Possible locations include the program participant's home or place of work, if applicable, or a local library or mall.

- Try to accommodate other obligations in the program participant's life, such as scheduled visits from home care staff, doctor's visits, employment duties, etc.

❖   <u>Get directions to the interview location.</u>

If appropriate, get directions during the initial call. Case managers or other staff can also provide directions. In addition, maps and Internet sites can be used to supplement verbal directions. The face sheet (*Appendix II)* includes room to record directions, as well as details about the interview time, date, and location.

❖   <u>Provide contact information.</u>

Be sure to leave contact information with the program participant, in case they need to cancel or change the arranged interview. Confirm the time, date, and location of the interview at the close of the conversation.

❖   <u>Remind the program participant.</u>

If possible, call the program participant a day or two in advance of the scheduled interview to remind him or her of the upcoming appointment. A letter or reminder card can also help insure the program participant is at home when you make your visit.

Special situations:

- ❖ Program participant declines

    Answering the survey questions should be a voluntary activity for program participants. If the selected individual declines to participate, mark the reason given on the face sheet.

- ❖ Program participant has significant problems with waiver

    If you determine during your initial phone call that the program participant has significant concerns or problems with waiver services, refer him or her to the appropriate program personnel for follow-up. Or, you may determine that it is more appropriate for state staff to initiate follow-up. There is space on the face sheet to record details about any needed follow-up by program personnel.

- ❖ Program participant has behavioral or other issues

    If case management staff or others indicate any behavioral or related issues relevant to arranging the interview, such as the program participant can be violent, or fears strangers, you should address them. For example, if the program participant should not be seen alone, then arrange to have the appropriate staff present.

- ❖ Program participant needs special arrangements

    Use the information from the face sheet to make any other special arrangements necessary, such as the presence of a translator or individual knowledgeable in sign language.

5.   **General Interviewing Guidelines:**

<u>BEFORE THE INTERVIEW</u>

❖   <u>Review instrument and face sheet (if applicable).</u>

Review both documents before you meet with the program participant. It is important to know the instrument well, so that you can spend most time looking at the program participant and not at the interview. If you are using the face sheet, there may information there to help you when conducting the interview, such as the case manager's name. You can use this information to personalize the survey, for example, by writing in staff names.

❖   <u>Assign a case ID.</u>

Case IDs are useful for tracking interview status, as well as facilitating any necessary follow-up. In addition, case IDs can be used to create linking variables to other sources of participant-level data. Finally, randomly-assigned, unique case IDs can be used to distinguish surveys in place of readily-identifiable participant data, such as name or social security number, and thus maintain HIPAA-mandated protections around the privacy of personal health information.

- The case ID should be unique to that program participant interview.

- Copy this number on the first page of the survey.

- Can be done in advance of the actual interview.

<u>INTERVIEWING PEOPLE WITH BRAIN INJURIES – SOME BACKGROUND</u>

People who sustain brain injuries can experience a wide variety of impairments, both cognitive and physical, as a result. In many ways, each brain injury survivor is unique. However, there are some common themes that characterize individuals with acquired brain injuries, which will directly impact their interview experience. These are discussed below.

In general, interviewing individuals with acquired brain injuries can be somewhat challenging due to the cognitive impairments which often limit insight, memory, attention, and concentration. Some people with acquired brain injuries may be unable to accurately report how they perform in real-life situations because they lack self-awareness. For example, they may lack insight as to what their capabilities and limitations are, and they may misjudge or misperceive their abilities. Often, they will overestimate their abilities, particularly around the need for help with personal care services or other activities of daily living. Short-term memory is also often adversely affected by a brain injury, with obvious implications for answering survey questions. In addition, people with brain injuries often experience fatigue, which impairs their ability to attend to a lengthy questionnaire. At the

same time, many people with acquired brain injuries are predisposed to frustration with their post-injury lives, as they grapple with the many changes in their cognitive and physical abilities and their social situations.

All of these factors form the backdrop to the interview situation. While not insurmountable, they should be carefully considered when conducting the interview. Specific guidance for conducting the interviews is provided in the next section, but below are a few overarching pointers to keep in mind while conducting the interviews:

❖ Allow people time to answer questions, to both retrieve information from memory and to formulate responses.

❖ Make sure respondents feel comfortable if they cannot remember the answer to a question.

❖ Be especially attuned to the respondent's emotional state and maintain a positive affect.

❖ Acknowledge emotionally difficult items and give respondents permission to skip them.

❖ Take breaks as fatigue and emotion dictate.

DURING THE INTERVIEW

❖ <u>Introduce yourself and help program participant feel at ease.</u>

Interviews will be more productive and smooth when the respondent is comfortable with the process and the nature of the survey. It is important to take some time to establish the context for the interview, and address any concerns the individual may have. Waiver participants may have concerns about how the data will be used, whether there will be negative repercussions for participating, and if their privacy will be protected. Others may fear looking unintelligent in the eyes of the interviewer. In addition, people who have sustained brain injuries often have impaired short-term memory and recall, and may be concerned or embarrassed about their ability to answer the survey questions. Therefore, starting the interview with some background on the survey, and reassuring participants about privacy and other issues is very important. Below are some key points to include in the introduction.

- Remind program participants again of the purpose of the survey (to learn about their experiences and determine if program improvements are needed).

- Underscore that there are no "correct" answers nor will there be retribution for their honest responses about problems.

- Address issues of recall, letting participants know it is OK if they cannot remember an experience, person, etc. Also, let them know there is no time pressure, and that they can take all the time they need to respond.

- Discuss confidentiality of responses, if appropriate.

- Allow time to answer any questions the program participant may have before starting.

- See suggested script, which can be paraphrased, below.

"My name is _____ and I am from the State of _____. Thank you for agreeing to spend some time talking with me. I would like to ask you some questions about your experience with the services you receive.

Your state wants to hear your opinions to learn how well their program is meeting the needs of people with brain injuries. There are no correct answers to these questions – I am interested in hearing about your experience. And, we can stop any time you like.

Some people, as a result of their injury, may not be able to remember the answer to some of these questions, or to answer them quickly. If you don't remember the answer to a question I ask, please tell me. Sometimes "I don't remember" could be the best answer. Also, we can take as much time as you would like to go through the survey.

Do you have any questions for me before we begin? If something I ask is confusing, please let me know."

❖ Address the presence of others.

Check with the program participant to see if the presence of any other people during the interview is consistent with his/her wishes. Some program participants may feel more comfortable with staff or family members present. Others may prefer to talk to you in private, but may need your help to make that happen.

❖ Make sure that you and the program participant are comfortable.

Try to minimize distractions for yourself and the program participant, such as television and radio. Your focus should be on the instrument and the program participant. Also, try to make sure the respondent is physically comfortable, and has anything s/he might need before the interview begins.

❖ <u>When in doubt, ask; do not skip</u>.

- Ask every question on the survey, unless a skip pattern indicates to do otherwise.
- Program participants may choose not to answer any question they wish. That is their prerogative. If you sense that a question is difficult or upsetting to the respondent, offer them the opportunity to skip the item.
- If possible, determine in advance if you will be asking the additional ADL/IADL or community integration questions, so you can have those materials ready. Your state may have already made a decision, based on program structure, which additional survey modules to use.

❖ <u>Do not leave any questions blank</u>.

If the program participant does not answer or chooses not to answer a question, record "No Response." If s/he cannot remember, use the "I Don't Remember" response option.

❖ <u>At first, ask the questions as they are written.</u>

This ensures that each person initially gets asked the question the same way. Consistency in the way questions are asked is one way to ensure any comparisons are valid.

At the same time, a key goal of the survey is to learn about program participants' experience. Sometimes this may require rewording the question, or asking additional, probing questions, to help the respondent understand what is being asked. Therefore, after reading the question in the original form, you may repeat or rephrase the question if necessary to help clarify the question's intent, as long as the meaning of the question does not change. You may want to note any questions that were unclear to the respondent in the Interviewer Comments section at the end of the survey (see below).

❖ <u>Try to clarify unclear answers.</u>

If a program participant's answer is unclear, you may probe to gain further understanding, by asking additional follow up questions. However, try to not impose your interpretation on the program participant. You may simply mark the response as "unclear" if the program participant's response is unclear.

❖ <u>Whenever possible, record only responses provided by the program participant.</u>

This instrument is designed to be a *participant* experience survey. If other people provide a response, verify the program participant's answer, if you can, before choosing a response option. You can gently remind family, friends, etc. who are trying to help with information that we are interested in hearing directly about the

program participant's experience. If you do record any proxy responses, note this in the Interviewer Comments section.

❖ <u>Be sensitive to the program participant's physical and emotional state.</u>

The interview process can be both physically and emotionally draining for waiver participants, particularly as they are asked to report on things they can or cannot do, and asked about changes to their lives after their brain injuries. In particular, people with brain injuries can experience frustration as they confront the limitations and losses in their abilities and personal lives.

- You may want to periodically ask the participant how s/he is feeling, and if s/he would like to continue.
- If the program participant seems tired, frustrated, upset, or in pain, you can always offer to take a break from the questions.
- If the respondent seems uncomfortable with a particular item, you can remind him/her that while the question may not seem relevant, you (the interviewer) are required to ask it everybody.
- Program participants also have the right to stop the interview altogether. In this case, thank them for their time and end the visit.

❖ <u>Amend previous answers, if appropriate.</u>

If the program participant provides additional or new information later in the interview which changes a previous answer, you can return to that answer and amend it. For example, if you learn or observe during the interview that the program participant does receive assistance with an ADL, even if s/he initially states s/he does not, return to that question and follow the appropriate skip pattern. Also, if s/he remembers additional information, such as a case manager's name, note that information where relevant. Be sure to let the participant know that you are changing an answer, and to verify your new coding choice.

❖ <u>Close the interview</u>.

At the end of the interview, thank the program participant again for their participation. Leave contact information so that the program participant can contact someone knowledgeable if s/he has additional questions.

❖ <u>Complete the *Interviewer Comments.*</u>

Use the space at the end of the survey to make any comments about the interview you feel are important, including the program participant's comfort level, any non-verbal cues or observations, or whether someone else provided responses on the program participant's behalf. You can do this after leaving the program participant, so as to have more time and privacy.

Improving the interview by building rapport

Establishing a friendly and respectful rapport with interview subjects is critical to getting accurate and honest answers. Program participants will feel more at ease when you are:

- understanding
- non-judgmental
- respectful of their culture
- appreciative of the information provided

Conversational, open-ended questions are included in the survey as opportunities to build rapport between you and the program participant. You may also ask additional questions, and use "small talk" to increase rapport. The interview questions are always the primary focus, and should not be altered or dropped. However, indicating an interest in family pictures, pets, etc. through appropriate comments and questions will help set a friendly, more congenial tone. Similarly, making and maintaining eye contact is another way of building rapport and indicating respect, when it is culturally appropriate.

Some things to remember

Know and Share your Limits

Interviewers should be clear about the purpose of the visit: to administer the survey instrument. Too much social interaction can sidetrack the interview, or misrepresent the visit as a social call. In addition, you should be clear about the limits of your ability to change the program participants' living situation, services, etc. Your goal is to gather information only; requests for assistance, or complaints about existing services should be directed to the program participant's case manager or other designated contacts. When program participants raise concerns or ask for help, encourage them to talk to their case managers. Otherwise, the individual may be left with the impression that you will "fix things" for them.

Program Participants in Immediate Danger

Intervention may be warranted for program participants whose health, safety, or well-being seems threatened. If you believe the program participant is in immediate jeopardy, through abuse, neglect, unsafe living conditions, or inadequate services, contact the appropriate state or program representative. Some people, such as certain licensed professionals, may be required to this by law.

6. **Coding Responses:**

Throughout the survey, you, the interviewer, must make judgments about the information the program participant gives you. For example, you must decide how to code a response or if a skip pattern must be followed. This section provides guidance, by domain, on how to interpret and code individual items.

Take Note . . .

People with brain injuries often have short term memory impairments as a result of their injuries. As a result, any recall items throughout the survey can be coded as "I don't remember" if the respondent is having difficulty recalling a decision or event. It is important to make use of this option, especially if the alternative is to record a response of questionable validity. Reassure respondents that it is OK if they do not remember the answer to any question you pose. The survey is not a test, and participants should not feel distressed if they cannot remember certain experiences.

A. Program Supports

Current Living Situation, Items #1 - #7

The purpose of these questions is to assess choice and satisfaction with the waiver participant's current living situation. The first item in this series asks about satisfaction with the respondent's current home, and is fairly straightforward. The second item asks about the respondent's choice in living situation.

> 2. Who choose (this/that) place to live?

If the respondent indicates that s/he had a role in the decision-making process, even if s/he were not the ultimate decision-maker, code as "I did or I helped to choose." You may need to probe to determine the respondent's role.

Item #3 is a screening question to validate the respondent's current living situation.

3. Who do you live with?
(CHECK CORRECT CATEGORY)

If you have information in advance about the respondent's current living arrangements, you can use this to tailor the question to his/her specific situation. For example – "I understand that you share a house with John and George (housemates) – is that correct?" Making this item more concrete will make it easier for the respondent to answer, especially if s/he has difficulty with recall.

- "Housemates" refers to other, non-related adults sharing a congregate setting. This could be an apartment or group home.

- "Family" refers to members of the respondent's family of origin, generally parents or siblings. It does not include respondents who live with a spouse or partner and/or their own children.
- "Spouse/girlfriend/boyfriend" includes anyone who lives with an adult partner. It can also include adults who live with their own dependent children.
- "Alone" can include people who have up to 24-hour in-home supports, but do not live with other, non-staff.

Waiver participants who live with housemates or family members should be asked item #4 ("If you had your choice, would you rather live alone, with your family, or with a friend?") Those who live with housemates should also be asked item #5 ("Do you like the people who share your home now?"). Those who live with family can be coded "Not applicable" to item #5.

Waiver participants who live alone should skip directly to items #6 and #7 on page 6. These two items are only for those waiver participants that don't live with family members or other, non-related individuals. Again, with item #6 you may need to probe to determine if the respondent had a role in the decision to live alone.

Case Manager Access: Questions #8 - #10

The goal of the first question in this section, #8, is to determine if program participants can correctly identify their case manager. If program participants cannot name their case manager, they are less likely to be able to contact that individual when they need assistance. You can use the information on the face sheet to make this question as specific as possible, by using the case manager's name. Code this question as "names case manager" if the program participant can correctly name his/her case manager, or indicates in way s/he knows the case manager's identity. For example, participants may show a card with contact information, or describe the individual. If not, or if the program participant is unsure, code the question as "does not name case manager" If another term is more familiar than "case manager," such as support coordinator, then feel free to substitute it.

8. Who is your case manager? Is it _____?

1	☐	NAMES CASE MANAGER/SUPPORT COORDINATOR
2	☐	DOES NOT NAME CASE MANAGER/SUPPORT COORDINATOR
97	☐	UNCLEAR RESPONSE
98	☐	NO RESPONSE
99	☐	I DON'T REMEMBER

Refer to the face sheet for the case manager's name.

For questions #9 and #10, if the program participant states s/he has not tried to contact his/her case manager, or has not asked the case manager for assistance, record their response as "not applicable."

9.　　Can you talk to your case manager when you need to?

1	☐	YES
2	☐	NO
3	☐	SOMETIMES
95	☐	NOT APPLICABLE – HAVE NOT TRIED
96	☐	UNSURE
97	☐	UNCLEAR RESPONSE
98	☐	NO RESPONSE
99	☐	I DON'T REMEMBER

10.　　Does your case manager help you when you ask for something?

1	☐	YES
2	☐	NO
3	☐	SOMETIMES
95	☐	NOT APPLICABLE – HAVE NOT ASKED
96	☐	UNSURE
97	☐	UNCLEAR RESPONSE
98	☐	NO RESPONSE
99	☐	I DON'T REMEMBER

Requests for Assistive Technology, Environmental Modifications, and Additional Services: Questions #11-#16

The purpose of these questions to assess unmet need for specialized equipment, home modifications, or additional waiver services requested by program participants.

11.　　Have you ever asked for any special equipment, assistive devices, or changes to your home, which might make your life easier?

Some program participants may find the terms or concepts in item #11 confusing. *Appendix IV* lists examples of assistive technologies available for people with disabilities. This appendix can be used to provide examples to help clarify the concepts of special equipment and changes to the home.

- In some cases, a request for equipment or services may still be open. If so, check the "in process" option for question #13 or question #16.

B. Choice and Control

Choosing staff and services: Questions #17 - #21

The purpose of the items in this section is to assess if program participants can exercise control or make choices about who helps them and with what. While the Medicaid program requires program participants have a choice among agencies that serve them, it does not necessarily require that program participants be able to choose among staff from an agency. Similarly, participants may not always be able to change individual staff when they want. There may be good reasons, such as staffing shortages or program policy, which makes changes in staffing difficult or unlikely.

Nonetheless, program participants who indicate that they would like more choice and control regarding staffing are another important measure of program performance. This section seeks to answer:

- Do program participants have opportunities for helping select staff?

- Can program participants at least partially direct the type of assistance they receive?

This can be a difficult concept for some individuals. Items may require rephrasing or the provision of examples. Also, in #17, it may be necessary to probe to best understand the respondent's involvement in choosing staff.

Assistance with Problems: Question #24

The purpose of this question is to determine if the program participant has someone to whom they believe they can take concerns, questions, requests, and complaints. To code this question, you will need to know the relationship of the named individual to the program participant. Probe, if necessary, to determine in which category the named individual should be placed.

24. If there is something wrong with the help you are getting, who do you talk with to get the problem fixed?
(CHECK ALL THAT APPLY)

Probe, if necessary, to place the response in the appropriate category.

1	☐	NO ONE
2	☐	FAMILY/FRIEND
3	☐	CASE MANAGER/SUPPORT COORDINATOR/OTHER STAFF
4	☐	OTHER (SPECIFY) _____
96	☐	UNSURE
97	☐	UNCLEAR RESPONSE
98	☐	NO RESPONSE
99	☐	I DON'T REMEMBER

- Although this is a "check all that apply" question, some response categories are mutually exclusive. Respondents who answer "non-one" or are "unsure" of whom they would contact, cannot have responses in more than one category. Similarly, if "unclear response" is checked, no other response should be filled in.

Staff Understanding of Brain Injury: Questions #25

This item looks at whether the program participant believes his/her staff understands the effects of his/her brain injury. Many brain injuries can have unique effects on the cognition, memory, and behavior of those injured. One goal of the survey is to determine if program participants feel that their staff understands these effects. For this item, it is helpful to record any narrative provided by respondents, as this can provide useful context for their responses.

C. Respect and Dignity

<u>Respectful Treatment at Home and Work: Questions #26 - #29</u>

These items ask if staff in the home and other locations treat the respondent respectfully. Using actual staff names from the face sheet can make these questions more concrete, and therefore easier to answer. You can take time before starting the interview to annotate the survey tool with this information.

<u>Abuse and Theft: Questions #31 - #42</u>

The goal of these questions is to determine if program participants are being robbed, or physically, sexually, or verbally abused. The focus of these items is on current abuse – reports of past problems which have been resolved should not be recorded. Each item in this section follows the same format.

31.   Does anyone take your things without asking first?

1	☐	YES
2	☐	NO →Skip to Q.34
3	☐	SOMETIMES
96	☐	UNSURE →Skip to Q.34
97	☐	UNCLEAR RESPONSE →Skip to Q.34
98	☐	NO RESPONSE →Skip to Q.34
99	☐	I DON'T REMEMBER→Skip to Q.34

__Reminder:__
Refer to your state's policy on reporting for any suspected incidents of abuse or neglect.

32.   What happens? When? Would you like to tell someone about this?

33.   Who takes you r things without asking first? (CHECK ALL THAT APPLY)

Probe to place the response in the appropriate category.

1	☐	STAFF AT HOME
2	☐	STAFF SOMEWHERE ELSE
3	☐	HOUSEMATE
4	☐	FAMILY/FRIEND
5	☐	OTHER
96	☐	UNSURE
97	☐	UNCLEAR RESPONSE
98	☐	NO RESPONSE
99	☐	I DON'T REMEMBER

Some program participants may find the questions about theft and physical, sexual, and emotional abuse to be offensive, upsetting, or difficult to answer.

- Be sensitive around these questions.

- Reassure individuals that they are asked of everyone.

- Be attuned to any indications of abuse.

- Work to make program participants comfortable discussing their concerns.

- Use the follow-up probe in each series of questions to get as much information as possible about any alleged incident, to determine its severity and if the respondent would like or needs any assistance or intervention.

- If the program participant provides a name for questions #33, #36, #39, or #42, probe to determine the relationship the alleged abuser or thief has with the program participant.

> IMPORTANT: Despite any pledge of confidentiality you may have made, you may be required by state law or policy to report some incidents of alleged abuse or neglect described to you. Refer to your state's policy regarding legal and ethical responsibilities around reportable incidents of abuse.

D. Community Integration

Employment Questions #43-#47

This series of questions looks at program participants' choices in employment or other formal daily activities.

- Review the response to #44 to decide if the program participant has a formal daily activity, such as a job, sheltered workshop, training class, or volunteer position. This activity does not have to be paid employment.

- For all program participants with any kind of formal daily activity, ask questions #45 and #46. Be sure to determine if the respondent played a role in choosing his/her daily activity (#46).

- Program participants without any job or daily activity should be asked #47. Be sure to record the activity named by the respondent, if appropriate.

Unsupervised Time in the Community: Questions #49-#51

The purpose of these questions is to assess program participants' community integration, and any unmet need for community involvement.

- Respondents who answer "no" or "sometimes" to #49 should proceed to the next question. The rest should skip to #51.

- If the program participant answers yes to #50 (they do know why they are not allowed to go out without supervision), probe to find out their understanding of the reason.

- Question #51 is for all program participants, regardless of whether or not they are supervised in the community. The goal of this question is to assess unmet demand for community activities.

Progress on Waiver: Question #52

52. Can you do more for yourself now than when you first started receiving services from this program? Would you say no more, a little more, or a lot more?

- "This program" may not be meaningful to program participants. If possible, substitute the name of the waiver program, or, if appropriate, the name of the provider that will be recognized and understood by the program participant.

- This question differs from the yes/no/sometimes response pattern of the majority of other items. Be sure to read the first three response options aloud to the program participant (no more/a little more/a lot more). Use the "unsure" and "unclear" response options if appropriate.

Wrap-up: Question #53

57. Is there anything else you want to talk to me about?

_____

Refer program participants to case managers or other agency personnel if appropriate. Remind them that you are not in a position to make any staffing or service changes, so they will not be left with the expectation that you will make changes on their behalf

Important: Ask this wrap up item only after you have asked any of the additional items listed below and in section E.

Additional Community Integration Questions: Question #A.1 through #A.12

States may decide whether or not to use these questions, depending on the structure of their waiver program. If not appropriate for waiver participants, they can be skipped over.

- "Shopping" in question #A.1 refers to shopping for items other than groceries. If appropriate, use examples which will help the program participant understand this concept.
- If the respondent answers "no" to question #A.1, #A.4, #A.7, or #A.9 (e.g. they do not like shopping, eating out, attending religious services, or do not have friends they with whom they like to visit), skip the remaining questions in each set.

E.   ADL/IADL Questions

The purpose of the unmet need section is to determine if a person is going without any personal assistance they might require to do everyday activities - activities of daily living (ADLs) and instrumental activities of daily living (IADLs). You'll need to determine in advance, from case management or other staff if the program participant receives services and supports related to ADLs and IADLs to decide if these items are relevant. If not, this module can be skipped over.

All the ADL questions in this section (except toileting) include a skip pattern similar to the one shown below. The IADL questions are similar, but do not including the item on the timing of assistance.

B.1.   Does anyone help you to take a bath, shower, or wash your hair? (SPECIFY)

_____

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Receives Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

1	☐	RECEIVES HELP FROM ANOTHER PERSON
2	☐	DOES NOT NEED RECEIVE HELP FROM ANOTHER PERSON →Skip to B.5
97	☐	UNCLEAR RESPONSE→Skip to B.5
98	☐	NO RESPONSE→Skip to Q.B.5
99	☐	I DON'T REMEMBER→Skip to Q.B.5

B.2.   Does anyone ever make you shower or take a bath when you are not ready?

1	☐	YES
2	☐	NO
96	☐	UNSURE
97	☐	UNCLEAR RESPONSE
98	☐	NO RESPONSE
99	☐	I DON'T REMEMBER

B.3.   Do you sometimes not get a bath or shower when you need one?

1	☐	YES
2	☐	NO →Skip to Q.B.5
96	☐	UNSURE →Skip to Q.B.5
97	☐	UNCLEAR RESPONSE →Skip to Q.B.5
98	☐	NO RESPONSE →Skip to Q.B.5
99	☐	I DON'T REMEMBER →Skip to Q.B.5

B.4   Is this because there is no-one there to help you?

1	☐	YES
2	☐	NO
96	☐	UNSURE
97	☐	UNCLEAR RESPONSE
98	☐	NO RESPONSE
99	☐	I DON'T REMEMBER

The first questions in each ADL or IADL group address whether the program participant receives personal assistance to accomplish the activity. Listening to the program participant, you will need to make a judgment as to whether the respondent really does receive personal assistance, based on his/her narrative response. If there is any indication that any help is received from another person or that someone else routinely performs the task, code as "Receives help from another person." This includes stand-by assistance and cueing help, as well as hands-on assistance.

People with brain injuries can have a "deficit unawareness" that prevents them from recognizing their need for assistance. It is for this reason that these items ask about receiving, rather than needing, assistance, unlike the PES versions for other disability groups. Therefore, it is important to be attuned to any indication that the program participant receives any help from another person, even it is only occasional.

For the first four ADLs (bathing, dressing, transferring, and eating), respondents who receive assistance with these activities are next asked about the timing/convenience of this assistance ("Does anyone ever make you . . .). The purpose of this type of question is to assess waiver participants' degree of control over when they perform these intimate daily activities.

For all respondents coded as receiving assistance with a particular ADL/IADL, ask the next question in each series to see if the program participant is sometimes going without performing certain activities when necessary.

The last question in each series ("Is this because there is no-one there to help you") is only for those program participants who indicate they sometimes go without performing the ADL and IADL. The purpose of the last question is to determine if lack of personal assistance is the reason why program participants are going without performing these activities.   The exception to this is item #B.35 (managing money), where there is no follow-up question about why participants are not getting the help they need to manage money.

For further clarification, see the examples below. These examples were drawn from actual tests of the Participant Experience Survey.

1) Example: A man with an acquired brain injury told the interviewer he could put his own clothes on, but that his mother laid them out for him.

   How to code: Because he received this cognitive assistance from another person, he would be coded as receiving help from another person, and asked the follow-up questions.

2) Example: During pretests, many program participants reported their home care staff did all the shopping and cooking, whether or not they were capable.

   How to code: The fact that they received help overrides any self-reporting of the ability to accomplish the task on their own.

3) Example: Several waiver participants said during the field testing that they were receiving help that they didn't believe they needed.

   How to Code: Despite their perception that this help was unnecessary, they should still be coded as receiving assistance.

Important: If the program participant is physically and cognitively capable of an activity, but another person still routinely does it, s/he should still be asked the follow-up questions. It is important to err on the side of coding program participants as receiving assistance, to capture the broadest estimates of unmet need for personal assistance.

Two daily activities, eating and groceries, also include questions about participants' ability to make choices about what they eat and what food they buy. These items are not applicable to individuals who are tube-fed or on special diets which would preclude choice. Be sure to use the appropriate "no" code if this is the case.

F. Interview Comments

These comments are intended to be completed after finishing the interview with the survey respondent. They can provide useful context for analyzing and interpreting survey results, as well as for identifying proxy respondents. It is important to take the time to complete this section with all relevant additional information and observations about the respondent and the interview process.

7.   <u>**Analyzing Your Results**</u>

Data from the PES BI can be used to calculate up to 58 performance indicators for the waiver program. These indicators are listed below. Program staff can use these indicators to identify potential problem areas in waiver program quality. Detailed instructions on how to calculate each indicator is listed in Appendix V.

In addition to the performance indicators, which combine responses from related questions, users are strongly encouraged to examine the straight frequencies from the survey results. The frequencies can yield additional useful information about the experience of the waiver population in areas not covered by the performance indicators. For example, the frequencies can indicate which categories of individual are responsible for alleged abuse or theft.

The item frequencies also provide information about the applicability of the survey. For example, the number of "not applicable" responses may indicate that an item is not relevant to the population being surveyed. And, the frequency of "I Don't Remember" responses can indicate whether the survey is appropriate or too challenging for the intended respondents.

Performance Indicators

<u>Program Supports</u>

1. <u>Satisfaction with Home:</u> Percent of program participants who do not like where they live.

2. <u>Choice in Home:</u> Percent of program participants who did not help choose the place they live.

3. <u>Desire to Live Alone:</u>   Percent of program participants living with others who would rather live alone.

4. <u>Desire to Live with Friends:</u> Percent of program participants living with family members who would rather live with friends.

5. <u>Satisfaction with Housemates:</u> Percent of program participants with housemates (not including family members) who do not like the people with whom they live.

6. <u>Desire to Live with Others:</u> Percent of program participants living alone who would rather live with other people.

7. <u>Ability to Identify Case Manager:</u> Percent of program participants who are unable to name their case manager when asked.

8. <u>Ability to Contact Case Manager:</u> Percent of program participants who report they cannot always talk with their case manager when they need to.

9. <u>Case Manager Helpfulness:</u> Percent of program participants who say their case managers do not always help them when they ask for something.

10. <u>Assistive Devices and Environmental Modifications:</u> Percent of program participants who requested special equipment or environmental modifications who report not receiving these items.

11. <u>Additional Services:</u> Percent of program participants who requested additional services, such as rehabilitation, job training, or transportation, who report not receiving these services.

<u>Choice and Control</u>

12. <u>Choice in Staff:</u> Percent of program participants who do not help choose their direct care staff, but would like to.

13. <u>Changing Staff:</u> Percent of program participants who did not know they could change their direct care staff.

14. <u>Directing Staff:</u> Percent of program participants who do not help direct their direct care staff, but would like to.

15. <u>Satisfaction with Staff:</u> Percent of program participants who report that their direct care staff do not always do a good job helping them.

16. <u>Staff Time:</u> Percent of program participants who report direct care staff do not spend all the time they are supposed to with the program participant.

17. <u>Contact for Reporting Staffing Problems:</u> Percent of program participants who would report staffing problems to "no one" or are unsure to whom to report problems.

18. <u>Staff Understanding of Brain Injury:</u> Percent of program participants who report that their direct care staff do not understand what it is like to have a brain injury.

Respect and Dignity

19. Respect by Staff in Home: Percent of program participants who report direct care staff do not always treat them respectfully in their homes.

20. Careful Listening by Staff in Home: Percent of program participants who report direct care staff do not always listen carefully to their requests for assistance in their homes.

21. Respect by Staff in Other Locations: Percent of program participants with direct care staff at work or a day program who report these staff do not always treat them respectfully in these settings.

22. Careful Listening by Staff in Other Locations: Percent of program participants with direct care staff at work or a day program who report these staff do not always listen carefully to their requests for assistance in these settings.

23. Unwanted Visitors in Room: Percent of program participants who say people come into their rooms unwanted.

24. Theft: Percent of program participants who report theft.

25. Verbal Abuse: Percent of program participants who report being verbally abused.

26. Injury: Percent of program participants who report being injured.

27. Inappropriate Contact: Percent of program participants who report being touched in a way they don't like.

Community Integration

28. Satisfaction with Employment/Daily Activity: Percent of program participants with a formal daily activity who report they do not like their current job, day program, volunteer work, or other daily activity.

29. Choice in Employment/Daily Activity Percent of program participants with a formal daily activity who report they did not help choose their current job, day program, volunteer work, or other daily activity.

30. Demand for Employment/Daily Activity: Percent of program participants without a current formal daily activity who report they want one.

31. Transportation: Percent of program participants who report not always having transportation when needed.

32. Understands Need for Supervision: Percent of program participants not allowed in the community without supervision who report they don't understand why.

33. Community Involvement: Percent of program participants who report they do not always have an opportunity for community involvement.

34. Improvement on Waiver: Percent of program participants who report they can do "no more" for themselves than when they first started on the waiver.

Additional Community Integration Items

35. Shopping: Percent of program participants that enjoy shopping who report they do not get to go shopping.

36. Choice in Shopping: Percent of program participants that enjoy and go shopping who report they do not get to help choose where to go shopping.

37. Eating Out: Percent of program participants that enjoy eating out who report they do not get to eat out.

38. Choice in Eating Out: Percent of program participants that enjoy and do eat out who report they do not get to help choose where to go to eat.

39. Visit Friends: Percent of program participants with people they enjoy visiting who report they cannot see these people when they want.

40. Religious Services: Percent of program participants that enjoy attending religious services who report they do not get to attend religious services.

41. Other Activities: Percent of program participants who report they don't get a chance to engage in other activities they enjoy.

 ADL/IADL Questions

42. Control over Bathing: Percent of program participants who receive assistance with bathing that report they are sometimes made to take a shower or bathe when they are not ready.

43. Bathing: Percent of program participants who receive assistance with bathing that report they are sometimes unable to bathe because there is no one there to help them.

44. <u>Control over Dressing</u>: Percent of program participants who receive assistance with dressing that report they are sometimes made to dress when they are not ready.

45. <u>Dressing</u>: Percent of program participants who receive assistance with dressing that report they are sometimes unable to dress because there is no one there to help them.

46. <u>Control over Transferring</u>: Percent of program participants who receive assistance getting out of bed that report they are sometimes made to transfer when they are not ready.

47. <u>Transferring</u>: Percent of program participants who receive assistance getting out of bed that report they are sometimes unable to transfer because there is no one there to help them.

48. <u>Control over Eating</u>: Percent of program participants who receive assistance with eating that report they are sometimes made to eat when they are not ready.

49. <u>Choice in Eating</u>: Percent of program participants who receive help in eating, and are not on a special diet or tube-fed, who report they are not able to choose what they eat.

50. <u>Eating</u>: Percent of program participants who receive assistance with eating who report they are sometimes unable to eat because there is no one there to help them.

51. <u>Meal Preparation</u>: Percent of program participants who receive assistance with meal preparation who report they sometimes don't get a meal when they need one because there is no one there to help them.

52. <u>Choice in Groceries</u>: Percent of program participants who receive help with grocery shopping, and do not have dietary restrictions, who report they are not able to choose what groceries to purchase.

53. <u>Groceries</u>: Percent of program participants who receive assistance with grocery shopping who report they sometimes do not get groceries because there is no one there to help them.

54. <u>Housework and Yardwork</u>: Percent of program participants who receive assistance with housework or yardwork who report that sometimes the housework or yardwork does not get done because there is no one there to help them.

55. <u>Laundry</u>: Percent of program participants who receive assistance with laundry who report that sometimes the laundry doesn't get done because there is no one there to help them.

56. <u>Medication</u>: Percent of program participants who receive assistance with taking medication who report they sometimes do not get their medication because there is no one there to help them.

57. <u>Money Management</u>: Percent of program participants who receive assistance with money management who report they sometimes do not get the help they need to manage their money.

58. <u>Toileting</u>: Percent of program participants who receive assistance with using the bathroom who report they are sometimes unable to use the bathroom because there is no one there to help them.

8. **<u>Reporting and Acting on Findings</u>**

Collecting program participant data using the PES BI is only the first step in the quality improvement process. When the results have been collated and analyzed, two key questions arise:

❖ How and to whom should the results be reported?

❖ What programmatic actions do the results suggest?

<u>Reporting Results</u>

While States may consider the PES BI an internal quality improvement exercise, there may be expectations around how the results will be shared as well as advantages to sharing them. Indeed, reporting issues should be addressed almost before data collection begins, so that an effective and systematic strategy for sharing results is developed in advanced.

❖ Some key questions to address in advance:
  o Who are your audiences?

  o What are they likely to do in response to the results you share? What do you want them to do?

  o How well do they understand the waiver program?

  o How comfortable do you think they are with statistical data?

❖ Different potential audiences will have different expectations of, and uses for, the results.

  o Results can be used to monitor, compare, or motivate providers.

  o Policy makers and legislators may want the results for accountability purposes.

  o Department heads may want the data to support funding requests.

  o Advocates may also see the results as a way to assess waiver performance.

  o Program participants and their family members will be interested in the results, possibly as a basis for making choices in the program.

❖ These different audiences will require several different reporting products.

❖ For each audience there are several key questions:

  o What format is best (print or electronic or verbal)?

  o How long and how much detail?

  o What kinds of graphics and explanatory text?

  o What can you assume about the technical knowledge and literacy level of audience members?

❖ Disseminating the results also raises issues of:

  o Timing

  o Media and promotion

  o Appropriate messengers

  o Spokespeople to explain and reinforce the message

❖ Evaluating the effectiveness of reporting is valuable guidance for future efforts.

❖ Assistance in collecting and reporting quality/performance data is available at: www.talkingquality.gov

Acting on Findings

When examining PES BI performance indicators for potential problem areas, there are a few important questions to ask before deciding to intervene.

❖ How much do I care about this problem?
  o Is it priority within this program?
  o Does it have political relevance?
  o Is it within my jurisdiction?
  o How does it compare to other indicators and other known problems?

❖ What do the results mean?
  o Are the results statistically significant?
    ▪ Meaningful and measurable differences exist between groups.
  o Are the results accurate?
    ▪ Estimates can be more or less accurate depending on sampling errors.
  o Are the results practically significant?
    ▪ Results are considered unacceptably high, even if differences are not statistically significant.

  o Even if results are statistically significant, do they really justify making changes to the program?
    ▪ Is the incidence of problems considered acceptable?
    ▪ Are the data compelling enough to justify spending quality dollars?
    ▪ Are the results supported by data from other sources?
    ▪ Are they even amenable to quality improvement interventions?

When acting on any problem areas indicated by the performance indicators, it is important to bear in mind the functions contained in the Quality Framework. If action is deemed warranted, the appropriate personnel should be involved in brainstorming interventions or program changes to address the perceived problem. After intervening, repeating the survey can provide valuable information about the impact of your intervention, through changes in the performance indicator values. For more information about the quality improvement process, see **Work Book: Improving the Quality of Home and Community Services.**[4]

Additional Data Sources

PES BI data can also be combined with other data sources, both to determine the scope and prevalence of problem areas and to measure the impact of quality interventions. Data from other sources can help corroborate PES findings, or provide additional information about the problem area.

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[4] The Work Book can be found at http://www.cms.hhs.gov/medicaid/waivers/hcbsworkbook.asp

Appendix I: Background on the Survey Experience

How people answer survey questions – the process of formulating a response

In answering a survey question, people must go through four cognitive steps:

- Comprehension
- Retrieval
- Estimation/judgement
- Response

First people must <u>understand what is being asked</u> - comprehension. Then they must <u>retrieve from memory information</u> relevant to what they are being asked. Using this information, they have to formulate or <u>estimate an answer</u>, and then <u>convey their answer</u> to the person asking the question. The accuracy of a person's response can be affected at every step of this process. In addition, people with disabilities receiving home and community supports may also have multiple staff coming in and out of their homes to provide support, further complicating the interview. An interviewer's sensitivity to the issues outlined below can help limit their impact on the interview process.

<u>Comprehension:</u> Comprehending a question requires that the respondent first know the individual words. Health literacy – understanding of health terms and concepts such as managed care or case manager– can be limited in many populations. But respondents also have to have a practical understanding of what the question is really asking and what the interviewer's intention is. For both people with acquired brain injuries, pain associated with their conditions, possible sensory impairments, and general fatigue can also interfere with comprehension.

<u>Retrieval:</u> People with brain injuries can often have impaired short-term memory and recall. Furthermore, research indicates that people tend to group experiences in their memories, and that only abnormal events stand out. These two factors can make it difficult for respondents to retrieve fact and events from memory.

<u>Estimation:</u> When information is retrieved, the respondent may have to evaluate that information, make comparisons with other information, and fit that information into one of the provided categories. This can also be challenging.

<u>Response:</u> Finally, even after arriving at a response internally, individuals may edit their spoken or written response for reasons of social desirability or self-presentation. In general, people want to try to reflect prevailing social norms in their answers rather than actual personal experience. In interviews, people don't want to be embarrassed, or seem abnormal, or unintelligent.

Participant Experience Survey – Brain Injury Version
Face Sheet

I.   BACKGROUND (To be filled out by the case manager or other appropriate program personnel)

I-1.   Program Participant's Name: _____

I-2.   Social Security Number: _____

I-3.   Program Participant's Medicaid Number: _____

I-4.   Program Participant's Address: _____

_____

_____

I-5.   Program Participant's Tel. No: _ _ _-_ _ _-_ _ _

I-6.   County of Residence: _____

I-7.   Date of Birth (MM/DD/YY):   _ _ / _ _ / _ _

I-8.   Contact for Scheduling Interview

If program participant should be contacted directly, check here _____

Name: _____   Relationship: _____

Daytime Phone: _ _ _- _ _ _- _ _ _ _   Evening Phone: _ _ _- _ _ _- _ _ _ _

Pager: _ _ _- _ _ _- _ _ _ _   Cellular Phone: _ _ _- _ _ _- _ _ _ _

Email address: _____

I-9. Special Instructions

Any special instructions for the interviewer in arranging the interview?

_____

_____

_____

_____

I-10. Legal Guardian

Does the program participant have a legal guardian? _____ Yes   _____ No

Legal Guardian's Name: _____

Legal Guardian's Address: _____

_____

Legal Guardian's Tel. No. : _ _ _ - _ _ _ - _ _ _ _

I-11. Case Manager

Case Manager's Name: _____

Case Manager's Agency: _____

Case Manager's Tel. No. : _ _ _ - _ _ _ - _ _ _ _

Please indicate if case manager is known by another title, e.g., support coordinator:

_____

I-12. Communication Needs:

Does the program participant need any special communication accommodations to participate in the interview? For example, is his/her primary language something other than English? Does s/he use sign language or a communication device? Please explain what arrangements would be needed for the interview:

_____

_____

_____

I-13. Service Plan

Please check all the services that the program participant receives through the waiver.

_____ Personal care/personal attendant services/home health aide/homemaker

_____ Chore/home maintenance

_____ Home-delivered meals

_____ Home modifications

_____ Day program

_____ Visiting nurse/OT/PT/Speech

_____ Employment assistance

_____ Assistive technology/durable medical equipment

_____ Family support/caregiver training/respite

_____ Transportation

_____ Community Support

_____ Case management

_____ Behavioral/other therapy

_____ Mental health services

_____ Other _____

I-14. Direct Care Staff

If there are any people who are paid to assist the program participant in his/her home, such as personal attendants or homemaker staff, please indicate their first names. If there are several workers, please list those staff that spend the most time with the program participant.

Names of home staff: _____

If there are any people who are paid to assist the program participant outside his/her home, such as day program staff or an attendant at work, please indicate their first names. If there are several workers, please list those staff that spend the most time with the program participant.

Names of day program/employment staff: _____

I-15.   Other Helpful Information

Is there anything else that would be helpful to the interviewer who will be arranging for, and conducting, the interview? For example, might this person be uncomfortable talking with a stranger? Are there any reasons this person should not be interviewed alone?

_____

_____

II.   **SCHEDULING THE INTERVIEW** (To be completed by the interviewer)

II-1.   **Dates Individual Contacted**:   _____

_____

_____

_____

II-2.   **Willingness to Participate**

Agrees to interview? Circle YES and complete rest of this page only**.**

Declines interview? Circle NO and compete last page only

II-3.   **Scheduled Interview Date and Time**:   _____

II-4.   **Actual Interview Date and Time** (if different)   _____

II-5.   **Location:**   _____

II-6.   **Driving Directions:**

_____

_____

_____

_____

_____

_____

II-7.   **Case ID#**   _____

II-8.   **Is Program Follow Up Needed?**

____ Yes, immediate follow-up   ____ Yes, but need is not immediate   ____ No

Who should follow-up and why?
_____
_____
_____

II-9. **Reason Interview Refused** (check all that apply):

____	Too busy	_____	Hospitalized
____	No longer on waiver	_____	Communication issues
_____	Family/other refused	_____	Not comfortable/other concerns
_____	Not interested	_____	No reason given
_____	Waiver Participant has concerns/problems with program, staff, or services		

II-10. **Is Program Follow Up Needed?**

____ Yes, immediate follow-up   ____ Yes, but need is not immediate   ____ No

Who should follow-up and why?

_____

_____

_____

Appendix III: Sample Program Participant Letter

November 26, 200X

Dear :

I hope you can help me out.

I am helping to conduct a survey of people in the Medicaid Home and Community-Based Services Waiver Programs in _____. The purpose of the survey is to get feedback from people with brain injuries about how satisfied they are with the help they receive from organizations like X, and with the people who are paid to help them.

We are looking for people like you who can tell us your experience with the help you receive.

Would you be willing to meet with me and allow me to ask a few questions about the help you get? It would take about 30 minutes of your time. We can meet at your convenience – the date, time and place are up to you.

I will not be sharing any of the information you give me with anyone who is paid to help you. The information you give to me will be kept confidential.

I will call you in about a week to set up a convenient meeting time if you are interested, or you may call me at

Thank you.

Sincerely,

Appendix IV: Assistive Technology Examples

Below are several examples of assistive technologies and devices, as well as environmental modifications, currently available for people with disabilities. They are grouped both by impairment type and by everyday living activity. They can be used as examples when asking question #11 on PES BI.

I.   Assistive Technology by Impairment Type

Mobility
Wheelchairs – both motorized and portable (lightweight)
Ramps to enter your home, job, or school
Canes and walkers, including walkers with pouches or shelves for carrying things
Grab bars to hold on to so you don't fall down
Lifts to move a wheelchair up or down stairs

Communication
Computer software to help you learn words for things and places in your town
Computer software that lets you practice talking with another person
Little machines that play the messages you want when you press a button
Talking cards to let people know what you want
A special board with pictures that tell people what you want
Toys and other devices that make your speech clearer and louder

Visual Devices
A machine that lets you use a telephone to surf the World Wide Web and hear information
Large print address books
Talking maps to help you explore your neighborhood
Braille keyboards, rulers, and speaker phones
Special devices that make everything on the television look larger
Videos which describe the action in the movie
A phone that tells you the day, time, and phone number of someone calling you
Talking dictionaries, thermometers, VCRs

II.   Technologies for Everyday Living

Cooking/Meal Preparation
Special, simple cookbooks which use pictures to help you
Cookbooks recorded on tapes, written in Braille, or with large print
Picture cards to use when ordering food in a restaurant
Grippers that make it easier to hold on to things like tools and cooking utensils
Pots and pans which are easy to lift if you have weak arms
A buzzer that tells you when you have filled a cup or pot to the top
A cutting board that makes it easier to see the food
Devices that tells you when a pot is boiling
Special knobs for stoves and microwaves for people who can't see well
Talking kitchen timers and microwave ovens
Special tools for opening jars and bottles and for pouring milk,
Appliances and counters low enough to use if you are in a wheelchair

Eating
Plate guards to keep the food from being pushed off your plate
Special utensils for eating

Bathing
Shower stool so you can sit down in the shower
Hand-held shower
Grab bars in shower

Dressing
Markers you can feel for matching your clothes
Clothes with Velcro closings
Special hooks or other tools for buttoning buttons
A tool to help you put on bracelets or necklaces
A tool to help you tie your shoes
A tool to help you use a razor
A tool that makes it easier to pull a zipper
Magnified mirror for putting on makeup

Taking Medication
A special alarm clock to remind you when to take your medicine
Special syringes you can fill with insulin even if you can't see well or at all

Transportation
Vans with lifts to carry your wheelchair
Cars or vans that you can drive using just your hands (no foot pedals)

Computer Devices
A computer keyboard with large colored keys
A computer mouse that attaches to your head, so you can control the computer by moving your head
A computer mouse that you use with your feet
A machine that lets you work your computer by talking (telling it what to do)
Special glasses that let you control your computer with your eyes
Talking keyboard for the computer
A talking computer which takes notes for you

Other
A device that lets you attach a camera to a wheelchair
Large light switches that are easy to use/switches you can turn on with your tongue
Special tools that help you turn a key, squeeze toothpaste, and other daily activities (fine motor tasks)
A scanner which tells you the amount of your paper money ($1, $5, $10 etc.)

Appendix V: Calculating the Performance Indicators

The table below shows the numerator and denominator for each of the 58 performance indicators.

Indicator Number	Indicator	Numerator	Denominator
PROGRAM SUPPORTS			
1	Satisfaction with Home: Q1	Number of "no" (2) responses to Q1.	Total number of "yes" (1), "no" (2), sometimes (3), and "unsure" (96), responses to Q1. Do not include "unclear" (97) or "no response" (98) to Q1.
2	Choice in Home: Q2	Number of "Someone else did" (2) responses to Q2.	Total number of "I did" (1), "someone else" (2), and "unsure" (96), responses to Q2. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q2.
3	Desire to Live Alone: Q4	Number of "alone" (1) responses to Q4.	Total number of "alone" (1), "family" (2), "friends" (3), and "unsure" (96), responses to Q4. Do not include "unclear" (97) or "no response" (98) to Q4.
4	Desire to Live with Friends: Q4	Number of "friends" (3) responses to Q4	Total number of "family" (2) responses to Q3. Do not include any "family" respondents in Q3 who answered "unclear" (97) or "no" (98) to Q4.
5	Satisfaction with Housemates: Q5	Number of "no" (2) responses to Q5.	Total number of "yes" (1), "no" (2), and "unsure" (96), responses to Q5. Do not include "not applicable" (95), "unclear" (97) or "no response" (98) to Q5.
6	Desire to Live with Others: Q7	Number of "family" (2) and "friends" (3) responses to Q7.	Total number of "alone" (1), "family" (2), "friends" (3), and "unsure" (96), responses to Q7. Do not include "unclear" (97) or "no response" (98) to Q7.

Indicator Number	Indicator	Numerator	Denominator
PROGRAM SUPPORTS (con.)			
7	Ability to Identify Case Manager: Q8	Number of "does not name case manager" (2) and "I don't remember" (99) responses to Q8.	Total number of "names case manager" (1), "does not name case manager" (2), and "I don't remember" (99) responses to Q8. Do not include "unclear" (97) or "no response" (98) to Q8.
8	Ability to Contact Case Manager: Q9	Number of "no" (2) and "sometimes" (3) responses to Q9.	Total number of "yes" (1), "no" (2), "sometimes" (3) and "unsure" (96), responses to Q9. Do not include "not applicable" (95), "unclear" (97), "no response" (98) or "I don't remember" (99) to Q9.
9	Case Manager Helpfulness: Q10	Number of "no" (2) and "sometimes" (3) responses to Q10.	Total number of "yes" (1), "no" (2), "sometimes" (3) and "unsure" (96), responses to Q10. Do not include "not applicable" (95), "unclear" (97), "no response" (98) or "I don't remember" (99) to Q10.
10	Assistive Devices and Environmental Modifications: Q13	Number of "no" (2) responses to Q13. Do not include "in process" (3) to Q13.	Total number of "yes" (1), "no" (2), "in process" (3), and "unsure" (96), responses to Q13. Do not include "unclear" (97), "no response" (98) or "I don't remember" (99) to Q13.
11	Additional Services: Q16	Number of "no" (2) responses to Q16. Do not include "in process" (3) to Q16.	Total number of "yes" (1), "no" (2), "in process" (3), and "unsure" (96), responses to Q16. Do not include "unclear" (97), "no response" (98) or "I don't remember" (99) to Q16.

Indicator Number	Indicator	Numerator	Denominator
CHOICE AND CONTROL			
12	Choice in Staff: Q18	Number of "yes" (1) responses to Q18.	Total number of "yes" (1), "no" (2), and "unsure" (96), responses to Q18 Do not include "unclear" (97) or "no response" (98) to Q18
13	Changing Staff: Q19	Number of "no" (2) responses to Q19	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to Q19 Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q19
14	Directing Staff: Q21	Number of "yes" (1) responses to Q21.	Number of "yes" (1), "no" (2), and "unsure" (96) responses to Q21. Do not include "unclear" (97) or "no response" (98) to Q21.
15	Satisfaction with Staff: Q22	Number of "no" (2) and "sometimes" (3) responses to Q22.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q22. Do not include "unclear" (97) or "no response" (98) to Q22.
16	Staff Time: Q23	Total number of "no" (2) responses to Q23.	Total number of "yes," (1) "no" (2) and "unsure" (96) responses to Q23. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q23.
17	Contact for Reporting Staffing Problems: Q24	Total number of "no one" (1) and "unsure" (96) responses to Q24.	Unduplicated number of respondents who answered "no one" (1), "family/friend" (2), "case manager, etc."(3), "other" (4), and/or "unsure" (96) to Q24. Do not include anyone with "unclear" (97) or "no response" (98), or "I don't remember" (99) responses to Q24.

Indicator Number	Indicator	Numerator	Denominator
CHOICE AND CONTROL (con.)			
18	Staff Understanding of Brain Injury: Q25	Total number of "no" (2) responses to Q25.	Total number of "yes," (1) "no" (2), "sometimes" (3), and "unsure" (96) responses to Q25. Do not include "unclear" (97) or "no response" (98) to Q25.
RESPECT AND DIGNITY			
19	Respect by Staff in Home: Q26	Number of "some-times" (3) and "no" (2) responses to Q26.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q26. Do not include "not applicable" (95), "unclear" (97), "no response" (98), or "I don't remember" (99) to Q26.
20	Careful Listening by Staff in Home: Q27	Number of "sometimes" (3) and "no" (2) responses to Q27.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q27. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q27.
21	Respect by Staff in Other Locations: Q28	Number of "sometimes" (3) and "no" (2) responses to Q28.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q28. Do not include "not applicable" (95), "unclear" (97), "no response" (98), or "I don't remember" (99) to Q28.
22	Careful Listening by Staff in Other Locations: Q29	Number of "sometimes" (3) and "no" (2) responses to Q29.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q29. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q29.
23	Unwanted Visitors in Room: Q30	Number of "yes" (1) and "sometimes" (3) responses to Q30.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q30. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q30.

Indicator Number	Indicator	Numerator	Denominator
RESPECT AND DIGNITY (con.)			
24	Theft: Q31	Number of "yes" (1) and "sometimes" (3) responses to Q31.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q31. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q31.
25	Verbal Abuse: Q34	Number of "yes" (1) and "sometimes" (3) responses to Q34.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q34. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q34.
26	Injury: Q37	Number of "yes" (1) and "sometimes" (3) responses to Q37.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q37. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q37.
27	Inappropriate Contact: Q40	Number of "yes" (1) and "sometimes" (3) responses to Q40.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q40. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q40.
COMMUNITY INTEGRATION			
28	Satisfaction with Employment/ Daily Activity: Q45	Number of "no" (2) responses to Q45.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q45. Do not include "unclear" (97) or "no response" (98) to Q45.
29	Choice in Employment/ Daily Activity: Q46	Number of "someone else" (2) responses to Q46.	Total number of "I did" (1), "someone else" (2), and "unsure" (96) responses to Q46. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q48.

Indicator Number	Indicator	Numerator	Denominator
COMMUNITY INTEGRATION (con.)			
30	Demand for Employment/Daily Activity: Q47	Number of "yes" (1) responses to Q47.	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to Q47. Do not include "unclear" (97) or "no response" (98) to Q47.
31	Transportation: Q48	Number of "no" (2) responses to Q48.	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to Q48. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q48.
32	Understands Need for Supervision: Q50	Number of "no" (2) responses to Q50.	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to Q50. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q50.
33	Community Involvement: Q51	Number of "no" (2) and "sometimes" (3) responses to Q51.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to Q51. Do not include "unclear" (97) or "no response" (98) to Q51.
34	Improvement on Waiver: Q52	Number of "no more" (1) responses to Q52.	Total number of "no more" (1), "a little more" (2), "a lot more" (3) and "unsure" (96) responses to Q52. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to Q52.

Indicator Number	Indicator	Numerator	Denominator
ADDITIONAL COMMUNITY INTEGRATION			
35	Shopping: QA.2	Number of "no" (2) responses to QA.2.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to QA.2. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QA.2.
36	Choice in Shopping: QA.3	Number of "someone else" (2) responses to QA.3.	Total number of "I always do" (1), "someone else" (2), "I sometimes do" (3), and "unsure" (96) responses to QA.3. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QA.3.
37	Eating Out: QA.5	Number of "no" (2) responses to QA.5.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to QA.5. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QA.5.
38	Choice in Eating Out: QA.6	Number of "someone else" (2) responses to QA.5.	Total number of "I always do" (1), "someone else" (2), "I sometimes do" (3), and "unsure" (96) responses to QA.6. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QA.6.
39	Visit Friends: QA.8	Number of "no" (2) responses to QA.8.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to QA.8. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QA.8.

Indicator Number	Indicator	Numerator	Denominator
ADDITIONAL COMMUNITY INTEGRATION QUESTIONS (con.)			
40	Attend Religious Services: QA.10	Number of "no" (2) responses to QA.10.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to QA.10. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QA.10.
41	Other Activities: QA.12	Number of "no" (2) responses to QA.12.	Total number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (96) responses to QA.12. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QA.12.
ADL/IADL QUESTIONS			
42	Control over Bathing: QB.2	Number of "yes" (1) responses to QB.2.	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to QB.2. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QB.2.
43	Bathing: QB.4	Number of "yes" (1) responses to QB.4.	Number of "receives help" (1) responses to QB.1. Do not include respondents needing help in QB.1 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.3 or QB.4.
44	Control over Dressing: QB.6	Number of "yes" (1) responses to QB.6.	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to QB.6. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QB.6.

Indicator Number	Indicator	Numerator	Denominator
ADL/IADL QUESTIONS (con.)			
45	Dressing: QB.8	Number of "yes" (1) responses to QB.8.	Number of "receives help" (1) responses to QB.5. Do not include respondents needing help in QB.5 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.7 or QB.8.
46	Control over Transferring: QB.10	Number of "yes" (1) responses to QB.10.	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to QB.10. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QB.10.
47	Transferring: QB.12	Number of "yes" (1) responses to QB.12.	Number of "receives help" (1) responses to QB.9. Do not include respondents needing help in QB.9 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.11 or QB.12.
48	Control over Eating: QB.14	Number of "yes" (1) responses to QB.14.	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to QB.14. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QB.14.

Indicator Number	Indicator	Numerator	Denominator
ADL/IADL QUESTIONS (con.)			
49	Choice in Eating:QB.15	Number of "someone else" (3) responses to QB.15. Do not include "no choice, special diet/tube-fed" (2) responses to QB.15.	Total number of "I do" (1), "someone else" (3), and "unsure" (96) responses to QB.15. Do not include "no choice, special diet/tube-fed" (2), "unclear" (97), "no response" (98), or "I don't remember" (99) to QB.15.
50	Eating: QB.17	Number of "yes" (1) responses to QB.17.	Number of "receives help" (1) responses to QB.13. Do not include respondents needing help in QB.13 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.16 or QB.17.
51	Meal Preparation: QB.20	Number of "yes" (2) responses to QB.20.	Number of "receives help" (1) responses to QB.18. Do not include respondents needing help in QB.18 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.19 or QB.20.
52	Choice in Groceries: QB.22	Number of "someone else" (3) responses to QB.22. Do not include "no choice, dietary restrictions" (2) responses to QB.22.	Total number of "I do or I help" (1), "someone else" (3), and "unsure" (96) responses to QB.22. Do not include "no choice, special dietary restrictions" (2), "unclear" (97), "no response" (98), or "I don't remember" (99) to QB.22.
53	Groceries: QB.24	Number "yes" (1) responses to QB.24.	Number of "receives help" (1) responses to QB.21. Do not include respondents needing help in QB.21 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.23 or QB.24.

Indicator Number	Indicator	Numerator	Denominator
ADL/IADL QUESTIONS (con.)			
54	Housework and Yardwork: QB.27	Number of "yes" (1) responses to QB.27.	Number of "receives help" (1) responses to QB.25. Do not include respondents needing help in QB.25 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.26 or QB.27.
55	Laundry: QB.30	Number of "yes" (1) responses to QB.30.	Number of "receives help" (1) responses to QB.28. Do not include respondents needing help in QB.28 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.29 or QB.30.
56	Medication: QB.33	Number of "yes" (2) responses to QB.33.	Number of "receives help" (1) responses to QB.31. Do not include respondents needing help in QB.31 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.32 or QB.33.
57	Money Management: QB.35	Number of "yes" (1) responses to QB.35.	Total number of "yes" (1), "no" (2), and "unsure" (96) responses to QB.35. Do not include "unclear" (97), "no response" (98), or "I don't remember" (99) to QB.35.
58	Toileting: QB.38	Number of "yes" (1) responses to QB.38.	Number of "receives help" (1) responses to QB.36. Do not include respondents needing help in QB.36 who provided an "unsure" (96), "unclear" (97), "no response" (98), or "I don't remember" (99) response to QB.37 or QB.38.

Some guidelines to keep in mind when analyzing the survey results:

❖ Be aware of skip pattern violations.

- Questions answered inappropriately (e.g. those which should have been skipped) can be recoded as missing, and not included in the numerator or denominator.

- Questions which were inappropriately skipped cannot be recoded (not enough information to impute the program participant's response).

❖ Respondents who are coded as "unclear response" or "no response" cannot be included in the numerator or denominator of the performance indicators. They are treated as missing observations.

- There is not enough information about these individuals to determine if they do or do not possess a given trait.